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Mental distress and 'self-stigma' in the context of support provision: exploring attributions of self-stigma as sanism

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Mental distress and 'self-stigma' in the context of support provision: exploring attributions of self-stigma as sanism

Abstract

Purpose

This paper discusses findings from a detailed qualitative PhD study exploring experiences of stigma and discrimination in the lives of people in receipt of 'mental health support' at two voluntary sector organisations in the North East of England.

Design

Empirical material was collected during two three-month long ethnographic periods of fieldwork from July to December of 2013 at two organisations providing support to their members who experience or have experienced mental distress. Along with field notes taken during and after periods of participant observation, the empirical material also included 30 interviews with staff (n=10) and members (n=20) across both organisations, along with a series of three focus groups at each organisation.

Findings

Staff at the organisations did not demonstrate obviously stigmatising or discriminatory attitudes or behaviours. However, they did attribute 'self-stigma' to particular attitudes and behaviours of some of the members they support, referring to how they 'made excuses', 'didn't try' and/or 'avoided situations'.

Originality/Value

This paper argues that these attributions resulted from the misrecognition of members' reactions to experiences of discrimination. The empirical material also suggests that these attributions of self-stigma may be indicative of the material limitations of the support environment, the consequent frustrations of well-intentioned staff, and, overall, as symptoms of neoliberalism. Drawing upon a Mad Studies approach and focusing on self-stigma and its attribution in contemporary mental health support, this article provides a new perspective, which considers how stigma is linked to discrimination by rethinking what is thought of as 'self-stigma'.

Keywords

stigma; self-stigma; discrimination; sanism; mad studies

Paper Type

Research

Introduction

Existing literature relating to mental health stigma, which relies on medical and/or psychiatric models of mental distress, indicates a distinction, but also a relationship, between 'public stigma' and 'self-stigma' (e.g. Corrigan and Watson 2002a; Corrigan and Watson, 2002b; Rusch et al, 2005). In summary, public stigma is considered to encompass reactions of the general public towards a group based on stigma about that group and/or predicated upon stereotypes, whilst 'self-stigma' refers to individuals turning the discriminatory attitudes of stigmatisers against themselves. Corrigan et al (2009) explain that self-stigma arises when people are aware of a stereotype, agree with it, and apply it to themselves which results in a 'why try?' attitude manifesting itself in the individual concerned. However, Corrigan et al (2009) also suggest that this attitude may be ameliorated by services, which can empower people and develop their personal identity [Corrigan et al (2006); Watson et al (2007:1317)]. Previous research has explored the negative effect of self-stigma on the self-esteem of people experiencing mental distress, which often leads to individuals feeling reluctant to pursue work or other opportunities; not because of illness, but because of 'self-discrimination' (Rusch et al 2005:531). Thus, tackling self-stigma and feelings of shame about experiencing 'mental health problems' has become a cornerstone of support services promoting an individual therapeutic approach (e.g. Morrison et al, 2016) and public campaigns to reduce stigma (See Me, 2019; Time to Change, 2019). The harmful effects of self-stigma have been acknowledged (Stewart 2019), exploring how arts-based initiatives can reduce incidences of self-stigma (Stewart et al, 2019). However, there has been little work both exploring and questioning the concept of 'self-stigma' in detail.

By exploring self-stigma from a Mad Studies perspective enables us to consider self-stigma using a more structural and less individualistic approach. This article uses empirical material to suggest how professional conceptions of self-stigma have the capacity to conflict with the interpretations of those in receipt of support. As a result, we consider whether professionals attributing 'self-stigma' in the way they do reflects an individualisation, which can be potentially harmful and stigmatising in the support environment. In doing so we also highlight the cost of self-management techniques in relation to notions of self-stigma, and suggest that self-stigma is better recognised within the context of discrimination, or more specifically, sanism.

Method

The overall aim of the PhD study was to explore and examine the support context with particular focus on experiences of stigma and discrimination. Empirical material was collected during two three-month long ethnographic periods of fieldwork in 2013 at two voluntary sector organisations in the North East of England providing support to their members who experience or have experienced mental distress. All participants and the two organisations were given pseudonyms. Both organisations, 'Bright Futures' and 'Creative Mindz', are city-centre based and registered charities. They were selected from a database of mental health organisations and approached with a research proposal. Durham University granted ethical approval to conduct the research. Along with field notes taken during and after periods of participant observation (three days at each organisation each week for three months), the empirical material also included a total of 30 interviews with staff (n=10) and members (n=20) across both organisations who self-selected to be involved, along with a series of three focus groups at each organisation. The recordings of the interviews and focus groups were transcribed for analysis. 'Self-stigma' emerged as a compelling phenomenon during the process of thematic analysis and systematic coding using the computer software package NVivo. It should be noted that discussion around self-stigma arose because both staff and member participants regularly used the term unprompted. Taking an iterative approach to the project, in later interviews, discussion was incorporated into the interview guide.

Findings

Self-stigma as a 'self-fulfilling prophecy'

The empirical material unequivocally suggested the majority of staff members believe 'self-stigma' to be a significant barrier to members receiving support and 'moving on' with their lives following experiences of mental distress. When staff members reflected on this notion of self-stigma, they identified that it manifested in both the attitudes and behaviour of members. For example, members were blameful of society for their predicament and/or felt powerless to change their circumstances and then avoiding situations or shying away from opportunity. It also seemed that many staff members considered self-stigma to be a 'choice'. As Dave (staff, int., Bright Futures) illustrated:

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3 *Some people sort of go around looking for it, they look for the stigma as*
4 *something to blame, blame society, 'well it's not me, I've got a mental health*
5 *problem, it's not my fault I can't do it, they're not letting us do it.' So, although*
6 *stigma, if you asked them are you being stigmatised, they'll say, 'oh no no', but*
7 *they're kind of self-stigmatising... And I think it's a self-fulfilling prophecy, that's*
8 *how I would sort of define it, because you can only be stigmatised if you let it...*

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16 The idea of using a 'mental health problem' or diagnosis as an 'excuse' for not seeking out or
17 taking opportunities for things like work, education, socialising etc. was common amongst
18 staff. Not behaving in line with the support rules or rules of the organisation and 'bad
19 behaviour,' was also considered by many staff participants as a facet of 'self-stigma'. As Faye,
20 (staff, int., Bright Futures), described:

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23 *They see themselves differently or use it as an excuse... We had a gentleman*
24 *who, I don't know what his diagnosis was because I never really worked with*
25 *him, he was a nice enough, very polite man but you always knew, you always*
26 *felt as though he was going to kick off...He was always I suppose a bit intense*
27 *and you got that feeling that you would tread a little bit carefully around him*
28 *and he did kick off this one day, someone had said 'you know there's no need to*
29 *shout and scream and swear at people', <raises voice> 'I'm allowed, I've got a*
30 *mental health problem and it's your job to deal with it'*

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43 Faye described a situation in which she believed the member behaved badly and used his
44 mental health 'problem' as an 'excuse'. She attributed this to his 'attitude' but there were no
45 other understandings or versions of events offered to explain why the member behaved in
46 this way.
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52 Particular staff members seemed to place a lot of emphasis on choice and self-determination.
53 For example, Nicola (staff, int., Creative Mindz) described a member who she considers to be
54 'self-stigmatising' and 'self-pitying' because the member believes she is unable to work as a
55 result of her mental health:
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3 *I think she's just very self-pitying, like she feels sorry for herself... Sometimes I*
4 *do want to sit her down and be like, you know what I mean like, everything is a*
5 *decision...I think she's too keen to play the victim, of like everything's hard...she*
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7 *could get a job, she could work...*
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12 In most cases, staff members continued to attribute self-stigma to members who do not try
13 and other associated behaviours and 'negative attitudes' with 'self-stigma'.
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18 Part of the common narrative of staff members with experience of mental distress involved
19 talking about how they had actively 'overcome' self-stigma or resisted the urge to self-
20 stigmatise. For example, Daniel (staff, int., Creative Mindz) recognised he had stigmatised
21 himself but had 'overcome' it:
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27 *I love my job here, but sometimes it's so frustrating because mental health*
28 *people are just so resistant against change, even if that change is going to help*
29 *them... obviously in my own personal experience, erm, I think a lot of stigma is*
30 *inward, I think a lot of stigma comes from within.*
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35 36 *Self-stigma as self-censorship and avoiding contexts where discrimination has occurred*

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38 Members, like staff, were keen to discuss 'self-stigma' but they considered it differently to
39 staff. In this section we suggest that the behaviours members associate with self-stigma could
40 be better conceived of as responses to experiences of discrimination, and self-management
41 techniques members have learned as a result of stigmatising or discriminatory experiences.
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43 Stevie (member, int., Creative Mindz) described 'self-stigma' via an articulation of her own
44 experiences relating to a time she felt excluded from a group:
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51 *When you stigmatise yourself you're afraid to go out, 'oh I'll not go out, I'll not bother,*
52 *I won't go in that pub full of normal people', but it's not because you are stigmatising*
53 *yourself, it's because you don't want to be in a situation where society has separated*
54 *you as somebody not normal...There's been groups I won't go to and groups I have*
55 *stopped going to because of that, and you feel well they're all normal and I'm not, they*
56 *may be nice people, nice with each other, I'm welcome to go there and do the task, but*
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3 if one invites the other, 'oh there's a film on in the cinema, isn't it to do with superman
4 or something', and I say, 'oh I like superman as well' says the one who's not normal,
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6 and then another one says, 'oh I like superman, oh are you going to come along and
7 see it with me at the cinema', and I say 'any chance I can come', and it's 'sorry
8 no'...because if you were normal they would have been happy about you going along
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10 with them and very often it's the one who isn't quite normal who doesn't get included
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12 in conversation at breaks, they talk about something and you talk about something
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14 relevant to the conversation and they don't look at you and they treat you as though
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16 they haven't heard what you said'
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22 When asked about 'self-stigma' most members said that they did stigmatise themselves to
23 some degree. When asked what made them think that they did self-stigmatise, the
24 behaviours they described were self-censorship i.e. thinking carefully about what details
25 about their mental distress they disclose, and to whom, and avoidance of certain situations
26 where they have experience of being discriminated against or where they think they will be
27 stigmatised or discriminated against. Both staff and members link feelings of self-stigma to
28 previous experiences of exclusion. However, there is a nuanced distinction between staff and
29 member perspectives, which is important for thinking about how self-stigma links to
30 discrimination.
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40 Comments from staff members suggested that self-stigma was attributed when members
41 accentuate or exaggerate their difference from others, which can often manifest itself in
42 'excuse making' or 'avoiding situations', in the eyes of staff. Yet here we see members working
43 to reduce or minimise their 'difference' from others, demonstrating the work they do in order
44 to try to fit in and participate in society.
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51 Conversations with participants indicated that often they did not like to tell people outside of
52 the organisation that they attended a place associated with 'mental health'. Felicity
53 (member, int., Creative Mindz) initially came to volunteer at the organisation but was advised
54 to become a member instead, highlights this point:
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If I say to someone, I am coming here, it depends on the people if I am going to continue saying what it is about, and or, I don't say it's a charity for mentally ill.

However, Linda (member, int., Bright Futures) said:

I would rather tell people I go to XXXX or here and then they can make up their own mind as to what's wrong.

Whilst members may reach different conclusions, as in the examples of Felicity and Linda, they are decisions which are negotiated and members seem to think quite carefully about how they manage that information. Thus, there is evidence of 'hidden labour' (Scully, 2010) which staff members do not seem to acknowledge when they attribute 'self-stigma'.

Discussion

Whilst staff acknowledge members' individual histories, including bullying, abuse, negative experiences with psychiatric services, welfare benefit entitlement, employment etc., it is still 'self-stigma' that is seen by the majority of staff as being more 'difficult' to 'deal with' in their day to day work supporting members. The empirical evidence in this study suggests that via compliance with what's on offer in the support context and other help available such as psychiatry, a member can become less 'self-stigmatising' or display the right kind of attitude which is then construed by staff as less self-stigmatising. Thus, we see support in this context potentially augmenting the medical/psychiatric model of support (Fabris, 2013). Self-management techniques, such as secrecy/concealing information are referred to by Link et al. (1989) as 'coping orientations.' Secrecy, selective disclosure and 'cost benefit' analyses are frequently reported as ways in which individuals cope with social and self-stigma (Holmes and River, 1999). Individuals may develop a disposition to see the world in a certain way resulting in a strong sense of 'felt stigma' and a predisposition to secrecy and concealment (Scambler and Hopkins, 1986). This also relates to the concept of 'passing' yourself as non-disabled in public (Goffman, 1963 and Brune, 2013).

Scholars such as Ritsher et al. (2003:47) refer to the notion of 'internalized stigma' which goes beyond the effects of direct discrimination and is more about internal perceptions, beliefs

and emotions of the stigmatised person (Ritsher and Phelan, 2004). Corrigan (1998) concurs and believes 'internalised stigma' relates to devaluation, shame, secrecy and withdrawal triggered by applying negative stereotypes to yourself. That said the literature still considers there to be some distinction between 'self' and 'public' stigma and discrimination. Conversely, the empirical material indicates that self-stigma and discriminatory experiences are so closely linked by those who experience it that to conceptually create a dichotomy, particularly in the way staff members seem to do, is misleading.

It also seems that when members do not take advantage of, or conform to, what support has to offer and other help available (psychiatry, talking therapies, back to work/skills training) they are labelled by staff as 'self-stigmatising'. A critique commonly levelled at psychiatry is that support assists to regulate those who disrupt hegemonic social relations and institutional processes (Diamond, 2013:74) and it appears this may be going on to some degree in contemporary voluntary sector support environments. As a result, it seems that the way staff attribute self-stigma may be part of the wider 'stigma problem' and, as Corrigan and Fong (2014:112) suggest:

...focusing on how people might eradicate their personal struggle with self-stigma may unintentionally perpetuate the notion that stigma is their problem, that it is another sequelae of the illness for which they must be treated.

Thinking about the distinction between staff and member interpretations of self-stigma, it seems staff primarily relate member passivity to attributions of self-stigma i.e. staff attribute self-stigma to members with the attitude of, and behaviours associated with, 'there's little point trying because the world is against me'. However, members' comments demonstrate how members are active agents managing some of the socio-political realities they encounter. There are two important issues to consider here, firstly acknowledging the 'work' members do on themselves to fit in and negotiate their social world (including 'passing'), and secondly highlighting the role of mental health policy and the socio-political climate.

Furthermore, members' comments also highlight how stigma can operate subtly at the micro level of social interaction, and so members were left feeling there was little anti-

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discrimination laws, policies and practices can do; and stigma can lead to some people hiding a problem or condition, or reducing its significance. Going further, the examples provided by the members demonstrate the considerable ‘cost’ of coping strategies and self-management techniques, and their impact on psycho-emotional wellbeing, and thus, may be better understood in the context of discrimination or disablism. Thomas (2007:73) extended the social model of disability to encapsulate this type of private social oppression:

Disablism is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being.

Reeve (2014) talks about how ‘direct psycho emotional disablism’ occurs as a result of interactions, often without malice, which serve to invalidate disabled people as people (Hughes, 1999) by undermining their self-confidence and self-esteem because of the negative messages they receive about their self-worth. Whilst members may not necessarily experience obvious structural barriers or barriers which overtly prevent them from talking about themselves openly or being present in certain social situations, the ‘psycho-emotional disablism’ operating on a private level, and understood as self-stigma, seems to create a barrier to ‘being’ for some of the members. As Mason (1992) suggests, ‘internalised oppression’ as a form of psycho-emotional disablism can often arise as a result of the relationship a disabled person has with themselves. For the members involved in this study, any ‘self-stigma’ seems to come about a result of invalidating interactions and public perceptions of what a person who has experienced, or experiencing, mental distress is thought to be.

In a similar vein to Disability Studies scholars (Goodley, 2011) and activists (Spandler, 2015, Russo and Sweeney (2016)), proponents of Mad Studies employ the term ‘sanism’. Sanism is considered ‘a form of systemic discrimination similar to sexism or racism, which targets psychiatric survivors’ (Perlin, 1991:92). It has also been described by Poole and Ward (2013:96-7) as being:

a devastating form of oppression, often leading to negative stereotyping, discrimination, or arguments that Mad individuals are not fit for professional practice or, indeed, for life...sanism also allows for a binary that separates people into a power-up group and a power-down group. The power-up group is assumed to be normal, healthy, and capable. The power-down group is assumed to be sick, disabled, unreliable, and, possibly violent. This factional splitting ensures a lower standard of service for the power-down group and allows the power-up group to judge, reframe, and belittle the power-down group in pathological terms...

It seems that staff attribution of self-stigma is a predominantly oppressive act and it is sanist to do so, this is because such an attribution constitutes professional narrative overriding personal experience of oppression and discrimination of the 'power down' group. Furthermore, what the findings in this study can be said to demonstrate empirically is how 'stigma power' may operate through the stigmatised person (Link and Phelan, 2014), yet how that power operates is nuanced and complicated. Perhaps the power differential between staff and members inhibits the ability of staff to recognise the experiences and the social location of the member, or that their place of privilege denies them the capacity to recognise members' situations differently.

This attribution of 'self-stigma' tends to ignore, or at least simplify, and perhaps professionalise, the struggle and conflict which members experience. Attributing self-stigma to those people who staff consider not to be responding positively to the support on offer in the support environment and/or are perhaps seen as 'passive', has the potential to feed into the stigma cycle and may be potentially stigmatising, sanist, discriminatory and/or excluding. When it comes to overcoming 'self-stigma', staff members did display sensitivity and were somewhat understanding of external influences. Despite this understanding, staff tend to continue to believe some members not to be 'trying' or that they are 'making up excuses', simply because they don't 'fit in' with what's on offer in the support environment. It must be said, that from our own experiences and engagement with the case study organisations, none of the staff were malicious or overtly discriminatory in their attitude, and there was a genuine belief that the support they were providing could overcome 'self-stigma' in most cases.

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However, it seems that if you don't 'try' or 'comply' in a prescribed way, members run the risk of being indicted for being 'self-stigmatising' and set apart from members who did try or comply.

'Self-stigma' is not something people *do* individually and in isolation of their social environment and instead it may be more appropriately considered a form of self-management shaped by wider socio-political contexts, particularly 'welfare reform'. These self-management techniques can often be misrecognised by staff members who attribute 'self-stigma'. Self-stigma seems to be an oxymoronic or paradoxical concept because what some of the existing literature, staff and members define as 'self-stigma' is predominantly resultant from negative and discriminatory experiences or the attitudes of others.

Whilst it may not be staff members' intention to contribute to a stigma cycle, when taking into account empirical material and the existing literature on stigma, labelling behaviours as self-stigmatising does not challenge the notion or existence of stigmatised identities. In the case of the support environments, attributing self-stigma could be said to serve staff members and neoliberal mental health policies by absolving them of responsibility when the support, or policies behind support provision, don't seem to be effective in the ways that those in more powerful positions think they ought to be.

Conclusion

It is clear that 'self-stigma' is described and understood by members and staff differently. Exploring 'self-stigma' from a member perspective led us to understand that what members describe as 'self-stigma' always occurs as a result of actual experiences or perceived reactions of others based upon experience. As a result, members seem to employ methods of information management/self-censorship and/or avoiding certain situations. We have suggested that the empirical material supports the idea that staff members' attributions of self-stigma may be better conceptualised as staff misrecognising members' reactions to stigma and/or discrimination. Furthermore, it is conceptually inaccurate, sanist, and paradoxical for 'self-stigma' to be considered synonymous with self-management techniques formed as a result of negative or discriminatory experiences because such classification locates the 'problem' within the individual. Both staff and member perspectives on self-

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3 stigma sees members contributing to their social condition, yet staff seem to see members'
4 contribution to their own situation as blameful in some way, or at least assume more personal
5 responsibility or agency on behalf of a member, whilst members do not. Thus, members are
6 not self-stigmatising but self-manage in a way which is sometimes misrecognised or
7 misconstrued by staff as self-stigma. Whilst passing and covering might be understandable, it
8 places demands on members and perhaps support environments could think more about the
9 ways members contribute to their social condition without blame. For example, setting the
10 attribution of self-stigma in the context of discrimination or sanism, not only highlights the
11 cost of self-management techniques for those of us who experience mental distress, but can
12 also provide an alternative perspective on how we think about self-stigma.

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23 From a practical perspective, staff members may benefit from a more formalised and
24 facilitated outlet to talk about how they negotiate their role. This may reduce the potential
25 for individualising problems in the form of self-stigma given that such attributions seem to be
26 born of staff frustration and their own personal experiences. Furthermore, staff attributions
27 of self-stigma are often based on a staff view of members being 'passive' and not 'wanting to
28 change'. Thus, building staff awareness of micro-power and emphasising that reactions to
29 stigma are not a 'choice' is integral to disrupting the stigma cycle. Responses to discrimination
30 shouldn't be misrecognised as 'self-stigma' and ultimately, individualised. Thus, briefings and
31 staff training for policy makers and practitioners which couch attributions of self-stigma in
32 the context of discrimination are integral to increase understanding of how these attributions
33 fit within a stigma cycle.

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45 Finally, the notion of 'self-stigma' removes us from any understandings of a social model of
46 madness and distress. It could be suggested that this individualised way of labelling
47 information management or avoidance of situations as 'self-stigma' or attributable to the
48 'illness' itself, moves in the opposite direction of social models of disability, madness and
49 distress. Attributions of self-stigma appear to place responsibility on individuals who have
50 experienced mental distress to help themselves more, and focuses on their ability to 'fit in',
51 which seems unjust from a member or service-user perspective if it is born of negative
52 experiences or attitudes. Placing responsibility for overcoming self-stigma on the person
53 concerned is a sanist practice, which distorts systemic and individual discrimination.

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Mental Health and Social Inclusion

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